**May 6, 2000**

Today, I took the girls to their swimming lessons at the YMCA. It started out just like any other Tuesday, but today wasn’t like a normal Tuesday. Kelli fainted in the pool! I was so scared! I had to rush her to the hospital, but thank God it was right down the street. The doctors had to revive her, because her heart stopped beating! Then they wanted to run all different kinds of tests on her, because they think she may have something wrong with her heart. I felt so helpless, my poor baby! There can’t be anything wrong with her heart. I couldn’t hold my tears back; I was just crying in the waiting room. All I wanted was Billy to be there. Oh, but my sweet, little Samantha was just there holding my hand saying “It’ll be okay Mommy the people in the white coats are gonna make Kelli all better.”

We were there for hours before the doctors told us anything. They weren’t positive about what’s wrong with Kelli’s heart so they want us to come back for more tests tomorrow. She looked miserable when I explained to her that she had to get more tests done tomorrow. I just wanted this all to go away and for my little girl to be healthy. I’m praying it’s nothing too serious.

**May 7, 2000**

The doctors told us that Kelli has Long QT Syndrome! I’d never even heard of this disease, let alone knew anything about it. I was in shock when they told us; I could not wrap my head around it. I have no idea what I would have done if Billy wasn’t there. I could barely focus when the doctors tried explaining what Long QT Syndrome was. The only thing running through my mind was that Kelli was going to have to quit swimming lessons. When I finally pulled myself together, all I heard the doctors say was sudden death! I freaked out, but Billy explained to me what I must have missed. He told me how the doctors said it’s an arrhythmic disorder that deals with the electrical system in the heart.1 He was saying how basically, Kelli’s heart takes a longer break between each heart beat than a normal heart would. The doctors continued to tell us that since her heart takes a longer relaxation period (that’s what they were calling it), this can lead to sudden death.2

This wasn’t even the worst part. Supposedly it’s a genetic disease, so now all our kids are at risk of it.3 I’m so scared and nervous! Now I’m terrified for my other children as well. I wouldn’t let them go outside and play with the other kids after dinner tonight. They were so mad at me, but I just couldn’t risk it after the doctors told us how it can lead to sudden death. They all have to go get tested for it now, but we couldn’t get an appointment until Monday! I don’t know what to do, because the doctors said exercise can lead to them fainting or even cause cardiac arrest which could kill them!4 Tommy has a baseball game this Saturday, but how do I tell him he can’t play this weekend? He’s going to be so upset; it’s the playoffs! I wish there was something I could do. I just don’t know how to deal with this.

**May 9, 2000**

I told Tommy that he couldn’t play in his baseball game tomorrow. He didn’t understand why he couldn’t. So I tried to explain to him how he might have Kelli’s disease and that we have to wait for the doctors to tell us if he does or not before he can play again. Since nothing about this week has been going my way, Kelli decided to walk in at this very moment. Tommy being the eleven year old boy he is decided that Kelli’s the reason why he can’t play tomorrow. He got up and yelled at her saying “If it wasn’t for you and your stupid heart, I could play in my game tomorrow. So if we lose it’s all your fault!” I know he would have said more if I didn’t interrupt him. It wouldn’t have mattered though Kelli was already upset. I felt so bad for her. She didn’t deserve to be yelled at; she’s not the one at fault here, Billy and I are. We’re the ones who passed it down to Kelli. Tommy should have yelled at us, not her!

**May 12, 2000**

This day couldn’t have come fast enough. I swear I’d have no hair left on head if we had to wait one more day. The boys were so excited that they didn’t have to go to school today until they realized they would be stuck in a doctor’s office all day. I was surprised when Samantha didn’t have the same reaction, although she has been acting strange lately. I have a feeling she understands how serious Kelli’s heart condition is. I know how absurd that sounds. I mean Samantha is only 6 years old how could she possibly understand what Billy and I can hardly grasp. It’s odd though she hasn’t been fighting with Kelli at all or even complained when I told the kids they can’t play run the bases after dinner. When the doctors came to do the EKG on her, she was completely fine during the whole test.3 I was expecting her to need me to hold her hand like Kelli did, but she just smiled at me and asked the doctors questions as though she does these tests all the time. I feel like she was trying to comfort me somehow; like she thought if she acted as if everything was fine then it would be.

When the doctors came back with the kids’ test results, I was so grateful to find out that both Christopher’s and Samantha’s tests came back negative for Long QT. I can’t imagine how either of them would have coped with it. My heart dropped though when the doctors told us that they wanted Tommy to come back for more tests. They tried to reassure us that there’s still a good possibility that he doesn’t have it but with the way everything’s been going I can’t afford to think like that.

**May 13, 2000**

Billy called me today after he dropped Tommy off at school. The doctors still aren’t positive if Tommy has Long QT or not but they want him to get more tests done by a cardiologist, Dr. Joel Temple. I don’t understand why they can’t figure out if he has it. They were able to tell us right away the results with everyone else. This driving me crazy! Why are Tommy’s tests taking so long? I can’t stand this waiting and not knowing. I just want to know so we can start dealing with this.

Billy has been beating himself up about this. I don’t know how to comfort him. I try to tell him it’s not his fault but he won’t listen. He’s being so irrational! I mean how could he know that he would pass this down to the kids?3 It’s not like he meant to. I wish he would realize how lucky we are that we found out before anything fatal happened. Everything just seems to be falling apart lately. I just want to be able to do something so I feel like I’m helping in some way. All I know to do is find out more about it and I feel like it’s no help at all.

Footnotes

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2 National Heart, Lung, and Blood Institute. (2011, September 21). *What is long qt syndrome?.*

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4 Mayo Clinic staff. (2012, April 12). *Long qt syndrome*. Retrieved from

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